Informed choice, deaf children and families

Informed choice, deaf children and families – underpinning ideas and project development.

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Abstract

This article concerns informed choice and the provision of services for deaf children and their families. It first outlines the background to why informed choice has become such an issue of importance in the English context. It then goes on to describe the first stages of a research and development project designed to produce guidance for both professionals and parents on an informed choice approach. These stages consist of a comprehensive literature review and a series of consultations with multi professional service providers and parents of deaf children. Fifteen key principles are presented that have been derived from these stages of data collection. They underpin our understanding of the complexities of what constitutes informed choice. Examples of the actual professional guidance document and parent handbook are also given. These serve to highlight the core difficulties faced in translating the underpinning issues into practical and useful documents for parent and professional alike.

Keywords: deaf children; informed choice

Introduction

This article describes briefly the background and initial stages of an English government sponsored project to promote Informed Choice in the context of families of young deaf children and the professionals who work with them. What is meant by 'informed choice' and why it has become such an issue in the English context is outlined below. This research and development project was commissioned by Early Support (www.earlysupport.org.uk), the central government programme designed to improve multi professional service provision for disabled children (including deaf children) from birth to 3 and their families. This particular piece of work is a collaborative venture between the National Deaf Children's Society (NDCS -the UK's leading charity for all deaf children and families) and the University of Manchester.

The project has to date included an extensive literature review (Young *et al,* 2006) and a consultation process with parents and carers of deaf children, and the professionals from many disciplines who work with them. The ultimate outcome of the project is to be two sets of documents: one aimed at parents and one aimed at professionals. These will support the implementation of policies and practices of informed choice in Local Authority (i.e. regional government) areas. They will also help parents gauge whether they are actually being offered an informed choice approach in making decision about their deaf children, or only a range of limited choices that professionals decide are appropriate. In order to achieve these objectives, the final documents will need to be user-friendly, useful and easy to put into practice.

Key to the project so far has been the development, from both the consultation process and the literature review, of what has come to be called the 'Underpinning Issues'. These are fifteen principles that need to be considered by any Local Authority committed to an informed choice approach. As their name implies these have come to form the foundation of both the Parent and Professional Guidance and are presented here for the first time. The challenge that now faces the research team is the translation of these underpinning issues into practical and useful working documents.

Background

First some background to the issue of informed choice. Over the past 30 years, research studies in the UK context have consistently shown that many hearing parents with deaf

children perceive, with hindsight, that professional services did not make them fully aware of the range of choices available in supporting their deaf child's linguistic and social development (Beazley and Moore, 1995; Gregory, 1976, 1995; Young, 2003, Young and Greally, 2003; Young, Jones, Starmer and Sutherland, 2005). Concern primarily centres on communication choices with several varieties of experience and complaint: the provision of information that is regarded as biased; the withholding of information about particular communication options; the unequal weight given to one communication approach over another; the attitudinal bias of some professionals towards particular support options; the policy position of Local Authorities that limit the kind of communication intervention approach that is supported and offered to families. Communication choice is not the only issue, however. The attitude and orientation of professional services towards *deafness* itself comes under scrutiny (Beazley and Moore, 1995; Young, 2002). That is to say parents report encountering predominantly medical models of deafness or deficit approaches in their early dealings with professional services, only to discover later cultural - linguistic models and alternative approaches to understanding the social identity of their children (Young, 2002). Though less well researched, there is also evidence to suggest that Deaf parents of Deaf children perceive choices concerning their children's support to have been withheld from them. This is either because they are not offered in the false belief that the information was not needed because parents were Deaf themselves, or because the information available was linguistically inaccessible to them (Young et al, 2005).

The issue raised by these experiences is not that a particular approach/ attitude/ position/ option is of itself right or wrong. Rather concern centres around three related issues. Firstly, that parents may be making choices without having access to all relevant information and, therefore, lack an appropriate basis on which to make choices; secondly, that not all choices are available to all parents because some are denied, unacknowledged or not resourced; thirdly that the professional – parent relationship is not an empowering one if the attitude and bias of the professional predominates. From these conclusions has come an increasingly strong call, in the English context, for the policy and practice of informed choice in the provision of information and multi professional services for families with deaf children. This position has been encouraged by the introduction of the universal newborn hearing screening programme (www.nhsp.info) and a strong current focus on early years' support for all disabled children (www.earlysupport.org.uk).

However, this framing of the issue as one of informed choice and the positioning of parents as empowered choosers is not without its own controversies. There is some evidence from parents themselves that they do not necessarily want an approach from professionals that seeks to empower them to make decisions for their children. Rather an expert model in which professionals guide them to what is best for their child is sometimes welcomed. It can work to take away anxiety that they, as parents, might not be doing the right thing (Dale, 1996; Powers et al, 1999).

Also, questions have been raised, particularly with regard to communication choices, as to whether an approach of unbiased information and equivalence of choice simply misses the point. Namely, that the parents' rights, enshrined in such an informed choice model, may actually bias and impede the deaf child's rights and potentially do harm (Hyde, 2004). This is a position most clearly seen with regard to sign language and Deaf culture. It has been argued that these are the deaf child's heritage and right regardless of the hearing status of the child's parents. Consequently this child's right is used as a fundamental justification in arguing for an education policy that promotes sign language for *all* deaf children (www.signcommunity.org.uk). Implicit in this view is the assumption that the deaf child's future language choice requires protection in a situation where parents, by virtue of being hearing may be unable to share the same perspective as the child. However, any blanket policy fails to offer informed choice by virtue of the fact that one option and one option only is being offered. Also amongst parents themselves there are many passionate supporters of singular and particular choices, be it cochlear implants, auditory verbal therapy, bilingual provision or whatever. Parents too are committed to some choices inherently being right and others not. Thus, the presentation of different approaches to deafness and communication as equally valid is regarded by those with a strongly held view as a misrepresentation of the evidence.

Against this background, the Department for Education and Skills (DfES) and Department of Health (DH) in England, in their joint approach to improving services for families with deaf children from birth to 3 years (DfES/DH, 2003a; DfES/DH, 2003b) have come out strongly in favour of an informed choice approach. As part of broader initiatives, the Early Support Programme (www.earlysupport.rg.uk) commissioned the NDCS (www.ndcs.org.uk), to produce guidance documents on the provision of informed choice. These were to be aimed at both parents and multi professional service providers. To achieve this end, NDCS decided

to work in partnership with a university department – Manchester University - to design and execute a research and development project aimed at producing such guidance.

Rationale

Superficially it may appear that informed choice in this context is simple; are parents offered choices for their deaf child and are they given the information they need to make those choices? As the members of the research team sought to develop their own understandings of what was encompassed by this deceptively simple term 'Informed Choice', it rapidly became clear that it was being used in many different ways and with a variety of assumptions in the literature. Parents and professionals from the consultation groups in their different contexts and from different perspectives also used the term to encompass a wide variety of ideas. We now consider the early stages of the project, in particular looking at the methods employed, and present the issues that have been identified as crucial to informed choice.

Methods

The two main strands of the research project were undertaken simultaneously and each strand is outlined below.

1. The Literature Review

The research team was aware from the start that the existing literature about informed choice in the field of young deaf children tended to be written from a particular standpoint (for example the policy positions of DELTA or the BDA). In addition, this body of literature considered informed choice in this specific context only, without any understanding of how the term was being used differently and more widely in other fields. For this reason a complex literature review was undertaken that looked at all the literature available across fields as widely diverse as food technology and medical treatment. The aim was to deconstruct existing bodies of literature in order to reveal, at a conceptual level, the frames of reference, theoretical debates and interpretative arguments that were common to the wider body of literature on informed choice regardless of the actual subject matter.

An electronic search was carried out using the search term "informed choice" across 10 data bases (MEDLINE 1966-2004; IBSS 1951-2004; ASSIA; Child Data; Sociological

Abstracts; Social Services Abstracts; PsycINFO 1967-2004; Web of Science (Social Sciences Citation Index) 1956-2004; CINAHL1982-2004; Social Sciences Index 1970-2004). This process resulted in 927 hits. The abstracts of these articles were read independently by 4 members of the project team who isolated those articles considered most relevant to identifying the range of concepts and arguments associated with 'informed choice'. Although such an inclusion criterion was wide and loosely defined, it was necessary given the focus on identifying relevance at a conceptual level rather than at the level of research focus, method, or results. At the second stage, the full text of 152 selected articles was obtained. Each article was classified according to eight thematic groupings: Content of information/information requirements; interface of the patient/person with the information; models of the information and choice relationship; requirements for the exercise of informed choice; roles and responsibilities of professionals/information providers; informed choice benefits; researching the existence/exercise of informed choice; criticisms of informed choice as an approach.

2. The Consultation Process

The second strand of the research project was an extensive consultation process with parents and families of deaf children and professionals who worked with them across three very different service contexts.

(i) A metropolitan authority encompassing large minority ethnic communities and where a range of approaches to the education of deaf children co-existed, but were not necessarily perceived as co-operative within a co-ordinated approach for families. The situation was further complicated by a restructuring of education services and complex issues in the provision of health services.

(ii) A medium sized shire county where the education services had a history of a particular strength in one communication approach, but who were seeking to explore a more all-encompassing approach to service provision.

(iii) A very large Special Educational Needs consortium who by dint of geography were grouped together, but whose membership reflected very different approaches to working with families and significant variation in available resources.

This diversity of context and service history provided rich experience for the consultation phases of the project.

In phase one, multi professional groups and parent groups in each area met separately for day-long facilitated events that explored: professional and parent understandings of informed choice; current barriers and enablers of informed choice for families with deaf children; and the implications in practice of an informed choice approach to parent-professional working partnerships.

A total of 27 parents and 47 professionals participated in this phase of the consultation. Overall, 4 languages (English, British Sign Language Urdu and Punjabi) were used in the consultation days. Professional representation was drawn from education services, social services, audiology, health and speech and language therapy. In addition there was representation from local Deaf Children's Societies and Parent Partnership. Both Deaf and hearing professionals participated. Parents varied in their experience of services with most having deaf children within the birth to 6 ½ age range and some of their deaf children also had disabilities.

All comments generated were recorded and treated formally as data, undergoing a detailed thematic content analysis. This analysis contributed directly to the identification and elaboration of the underpinning issues outlined later in this article, as well as providing the bulk of the direct examples that will illustrate these issues in the published guidance documents.

Phase One consultation days were further extended by smaller cross-site meetings with strategic leads from different services in order to gain insight into the strategic barriers and drivers to implementing an informed choice approach with families with deaf children.

Phase Two consisted of joint parent and professional consultation days in which: the major findings of the Phase One days were fed back and comments invited. Parent and professional expectations of a guidance document were explored including issues of 'usability', format and fitness for purpose.

The Way Forward.

At the time of writing this article, the research team is about to embark on Phase Three of the consultation process. In this phase parents and professionals will receive the full draft guidance documents and feedback will be invited. This will then be used to make adjustments and amendments prior to publication. In order not to influence this feedback unduly, comments will be sought under three broad headings:

a) Are they informative? This refers to the content, seeking to discover whether the right *sort* of information is there.

b) Are they useful? This refers to aspects such as the format, the register, and so on. For example, can parents and professionals find what they are looking for?

c) Are they helpful? This refers to fitness for purpose. Parents and professionals are asked to consider questions such as: Is it relevant to my situation? Has it enlarged my understanding of informed choice? Has it given me ideas on how to move towards an informed choice position?

Parents and professionals will be consulted separately and asked for comments primarily on the guidance written for them, although comments on the guidance written for the other group will, of course, be welcomed.

Informed Choice - The Underpinning Issues

We now present the fifteen issues that we identified underpin an informed choice approach to service provision, with their accompanying definitions and explanations. For those interested, a more detailed study of the literature reviewed is currently under review (Young et al, 2006); the empirical data obtained will be reported at a later date and the parent and professional guidance documents are due to be published by the DfES as part of the Early Support materials in early summer 2006.

1. Information, knowledge and understanding

High quality information is a crucial component in supporting families to make informed choices about their deaf child. The information must be available, accessible, comprehensive, relevant and meaningful to those who will use it. Information is helpful in building the knowledge that is needed to make choices, but the provision of information alone does not necessarily guarantee understanding. Parents may know about something in theory, but not yet have the experience to understand fully the implications, risks and benefits of any particular choice in their particular circumstances. Simply providing information does not necessarily mean that families are enabled to make informed choices for and about their deaf child. The key relationship is between understanding and choice, not simply information and choice. How we support parents to increase their understanding of the information provided is a crucial process in supporting informed choice.

2. Availability

Information and support to parents strives to be comprehensive in its scope, outlining the full range of options on any particular issue (such as communication choices) and avoiding partiality or bias. But there is a difference between informing parents of all possible options for their deaf child, and all options actually being available from services in the locality where they live. In situations where a potential choice is not available, the issue of whether it should be available and how it can be made available, is a crucial one for services to confront and parents to question. The extent to which service providers are upfront and honest about the range of provision that is possible in contrast to what is actually available is also a crucial component in parents reaching informed choices about their deaf children.

3. Access to availability

A range of services and support may be available, but there may nonetheless be barriers to these actually being possible, realistic or suitable choices from the family's point of view. These barriers may have absolutely nothing to do with a child's deafness, but may be more a reflection of a family's economic or social circumstances. Issues of matching cultural and linguistic preferences may also render theoretically available choices, practically inaccessible. Services that are not organized flexibly to meet individual family's circumstances may also serve to limit the range of options that are feasible for any given family. Finding solutions to issues of access to choices is as crucial to offering informed choice, as making options available in the first place.

4. Parents vary in their ability to make informed choices

One of the recurring and common experiences of parents of deaf children is the need constantly to make choices in relation to their child. Whilst this may be true of any parent of any child, in the case of deaf children there are many more decisions to consider, many of which have a bewildering range of potential options. But not everyone is equally used to making choices or being choosers. People vary in their confidence and skills in making choices – this often depends on past experiences and previous opportunities to exercise choice. Other factors such as self esteem also play a role. Knowing how to empower and support parents to be confident choosers is a key component of promoting informed choice.

5. Informed choice in families' terms

Informed choices in relation to deaf children are not just made on the basis of high quality, relevant information. Families will also make choices in terms of their pre-existing values, beliefs, culture, priorities and interests. Understanding the risks, benefits and consequences of any particular option will be thought about in the context of any family's particular value and belief system, as well as their social circumstances. Professionals may feel that they have offered families informed choice, but parents may not perceive it that way if the decision making process has not reflected family 'ways of doing things'.

6. Does informed choice mean we offer the same to everyone?

It is often assumed that informed choice fundamentally implies that everyone is offered an identical set of potential choices, be it, for example, with regard to communication approaches, audiological options, or educational placement. In this way, the differentiating factors become what best suits the individual child and family and who decides that. However, to think about informed choice only in terms of the equivalence to all of what is *offered*, is to miss the significance of the lack of equivalence in how families may take up what is offered. Families strengths and needs vary enormously and whilst many will feel well equipped to engage with informed decision making processes, many others may feel, at least initially, ill equipped to do so. Therefore, whilst informed choice may imply that everyone ultimately has the same opportunities, it should be recognized that the routes to informed choice will require different approaches to meet differing family needs. However, in professionals making assessments of what families might need, how and when, they should be aware of the

danger of taking on a gatekeeping role, which may in fact serve to impede rather than promote informed choice.

7. Are all issues open to informed choice?

In theory, informed choice may seem to be a desirable framework for the consideration of all issues. However, there may some issues in which having an informed choice may give rise to more complex considerations or even ethical dilemmas involving risk and harm. There may be instances where the rights of the child are in conflict with the wishes and choices of parents. On another level, there may cases where an expressed preference may be at odds with an assessed need. At all levels, parents and professionals need to reflect on and openly share their assumptions about what is and is not open to informed choice.

8. Individual choices and the effects on others' choices

An informed choice framework is frequently criticised for seeming to promote a highly individualistic approach to the right to choose that ignores how one person's decisions have consequences for the exercise of informed choice by others. In a context of limited resourcing or scarce skills, professionals may find themselves making decisions that respond to the bigger picture of overall needs for several children, rather than only to the preferences of an individual parent. On the other hand, a choice that one parent might make for a particular kind of support, perhaps previously unavailable in an area, may have positive consequences for many other parents to whom this now becomes more widely available. This tension between the individual as chooser and the wider social consequences of any particular choice may be hard to reconcile for either parents or professionals. However, upholding the rights and responsibilities of *individual* parents within an informed choice framework is of prime importance.

9. Parents as experts

The recognition and valuing of parents' expertise about their own child is fundamental to all considerations of informed choice. However, this expertise is not something static, nor fully formed, it is something that grows with their experience of their child and with their experience of deafness. Thus collaborating to develop and promote parents' expertise is as important as simply acknowledging it. If parents, quite rightly, will draw on their expertise about their particular child in making informed choices, then that expertise is something to be nurtured.

10. Informed choice is an active process

It is essential for professionals and services to see informed choice as occurring within an evolving framework of provision. Family situations change, children grow and develop, parents gain knowledge and understanding and all of these mean that choices may need to be reconsidered. Professionals should be empowering parents to choose, re-choose and change their minds when appropriate. Making a choice at a particular time should not mean that parents have to give up their right to make other choices at other times.

11. Attitudes and values

These operate at all levels. Professionals need to be aware of and be honest about their own beliefs and opinions and realize that these should not be presented in ways that influence the decisions parents make. Professionals should show parents respect at all times and in all situations. Strategically, the allocation of resources to a particular option may give a message that one choice is better than another choice.

12. Equality of resourcing

Equality of opportunity for families is a central tenet within an informed choice framework. Services need to ensure that every child and family has an equal chance to achieve potential. However, since child and family needs are different and individual, this implies a flexible response to resourcing (be it physical, social economic, or human resourcing). Criteria-driven resource allocation (e.g. based on level of deafness) may result in a resource-led rather than a needs-led model that diminishes opportunity for informed choice. Families whose situation may look on the surface to be similar may have very different resource needs in order to reach the same level of confidence and outcomes for them and their children. Achieving equal opportunity may require unequal resource allocation, in absolute terms.

13. Operational constraints

It may seem like a get out clause to suggest that some information is not provided, some choices may not be available, or some services may not be accessible because of 'operational constraints'. However, poor resourcing, low staffing levels, lack of training and skills shortages are very real constraints on service providers. Nationally there is, for example, a shortage of qualified Speech and Language Therapists; some equipment may be in short supply; there is not an infinite budget. However it is important to consider what is a real opera-

tional constraint, and what might only masquerade as such. Which could be overcome through, for example, changes in the way of working, challenges to old systems, or creative partnerships?

14. Resources strategy / philosophy

An underlying philosophy and its strategic implementation may have a significant effect on a family's opportunity to make an informed choice. An LEA's commitment to mainstream inclusion may, for example, lead to lack of available resources for any other choice. Furthermore, committing strategically to one specific approach or philosophy may by implication give the message that any other way is of lesser value. This issue is wide ranging in relation to informed choice and should not be seen only in terms of educational placement and communication methodology.

15. Training

Training underpins many of the key concepts associated with informed choice e.g. the provision of high quality, relevant information; increasing professional abilities to promote the empowerment of parents as active choosers; improving access to availability; resource allocation decision making and so forth. As such it is one of those factors (like attitudes and values) that oils the wheels of informed choice as a successful process for both parents and professionals. All those involved in service planning and delivery, from practitioner to operational and strategic managers have Continuing Professional Development needs. These may be met in a variety of ways including parent-led initiatives.

The Guidance Documents

Clearly these fifteen underpinning issues, although thought-provoking in themselves, do not form a guidance document that will facilitate informed choice for parents of deaf children or offer ideas to professionals on how to offer informed choice. Rather, the fifteen issues provide a philosophical basis of what informed choice might mean in practice. Currently, it is envisaged that the parent document will present the underpinning issues in a way that will be given practical relevance by the inclusion of examples and case studies together with suggested questions, tools for empowerment and resources. Here is a short sample from the proposed parent guidance that is linked to underpinning issue 4,

A Sample from the parent guidance:

Tabla I

Do I feel comfortable and confident with my choices?

Are you feeling comfortable and confident about the choices you are making? Perhaps you find making decisions difficult or you feel overwhelmed by the amount of information you have been given. The choices you are being asked to make for your deaf child may be about things outside of your experience. You may feel that you don't know how to make the best decision for your child and family. If you need more time, more information or help in making choices for your child and family your professionals should support you.

If you are not feeling comfortable or confident with the choices you have made/are making, you might like to think about the following:

- Contacting the NDCS to find out about their Family Support Network. There may be a 'family supporter' in your area who could support you in the choices you are making. Additionally, the local Deaf Children's Society may be a helpful place to find support from other parents of deaf children
- You could also talk to your professionals. Here are some things that as a parent you may want to say:
    - I feel there is too much information to take in all at once, I would like more time to think about this information/issue before I make a decision
    - I don't feel that I understand this issue yet and so I don't feel comfortable with making a decision, I would like some more information to help me to understand it better.
    - I would like to meet another family who have been through a similar situation, this might help me to make a decision for my child and family
    - I don't feel confident about making this decision. I would like to see my social worker/teacher of the deaf/speech and language therapist (etc) to give me more support in making a decision about this issue.
    - I'm feeling under pressure to make a choice on this issue. I need more time and more information before I can make a decision.

In addition to providing suggested resources, it is envisaged that the guidance will provide parents with the legislation or government initiatives that support the aspect of informed choice under discussion. This is at the specific request of parents who feel that such a knowledge base will empower them in their individual situations.

Currently, the professional guidance (which will be known as a handbook) is envisaged to be an explanation of the underpinning issues, followed by a section on developing professional practice. This will be arranged under topic headings such as 'Appointments', 'Multi-agency Working' and 'Training', all considered specifically within the context of informed choice. As well as summaries of what parents and professionals have told the research

team, there will be some practical examples of how services might move towards an informed choice position, suggested resources and governmental legislation and guidance that supports any proposed change.

A sample from the professional handbook :

Tabla II

Information in the context of informed choice

The nature, purpose, provision and use of information are fundamental considerations in the practice of informed choice. Although information alone does not facilitate choice, without information it is largely impossible to weigh up alternatives, be aware of options, or even simply engage with the processes involved in making decisions. For information to be effective within the context of informed choice, we know that it should possess certain characteristics. It should be up to date, unbiased, evidence based, relevant, and meaningful. Additionally information that addresses the risks and benefits of particular courses of action, as well as highlighting uncertainties is known to be helpful. Finally, information cannot fulfil any of its key functions if it is not accessible to those for whom it is intended. A focus on accessibility draws attention on the one hand to issues of language and format. On the other hand accessibility in relation to information also encompasses such issue as how information is made available and whether the very processes involved in accessing information of themselves create barriers in the promotion of informed choice. Information is just one component in the promotion of knowledge and understanding which parents will utilise to enable them to make choices.

Parents told us that: (a sample of the bullet points in the handbook)

- Bias effects what they get information about and how information is presented. This includes the feeling that if some options are not funded by an authority then information is not given about those options.
- Finding out information by chance leads to inequality

Professionals told us that: (a sample of the bullet points in the handbook)

- They found it difficult to give out full information about all options when they knew that some were not supported in their area or they did not have the requisite skills to deliver them.
- They are concerned about the tension between tailoring services to meet individual families' needs and offering a service of a consistent level.

Conclusion

Developing understanding of the concept of "informed choice" through the cross-disciplinary literature review and the consultation with parents and professionals has been valuable and instructive. Interestingly, members of the research team found that the deeper understanding that they developed had a personal impact. They found that in their own lives it influenced the services they expected and the ways in which they made decisions.

The main challenge at this stage of the project is that, having honed the concepts that underpin informed choice, it is necessary to translate them into practical documents of use to parents and professionals in their everyday lives, whilst simultaneously informing and influencing strategic decision making. They should be an indispensable resource that is constantly in use. For this to be achieved, the resulting guidance will need to be written in a way that is readily understandable; issues that come up in everyday life have to be found easily; problems that are identified have to have real world workable solutions. A narrow line separates this aim from writing an audit tool or a simple checklist of services that should be on offer in each area. Clearly, solutions appropriate to problems are context specific; what might be the perfect answer in one situation might be totally inappropriate in another. What is needed is a tool-kit that can be adapted by each user to her/his specific situation whilst retaining the simplicity and easy-to-use-ness required for these documents to have a real impact for all who use them.

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